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FROM THE EDITORS

Greetings and happy spring and fall for our readers in the northern and southern hemispheres respectively! We are delighted to present this fifth issue of the Innovia Newsletter, and hope that there will be something here to pique everyone's interest.

Part of Innovia's growth is reflected in our efforts to convene for a second time at Bellagio, Italy. We open this Newsletter with a call for papers by Innovia Director, Stuart Blume, who discusses where we are in our conference planning process, and outlines the four topics that have been agreed upon for the conference – the overall theme of which is 'Prevention and Public Health'.

Also in this issue are several contributions from around the world. We are excited to introduce the Newsletter's readers to someone with long-standing interest and

involvement with Innovia, Dr Chan Chee Khoon of Universiti Sains Malaysia. Those with an interest in patient advocacy in research will want to take note of Dr Chan's involvement in the area, especially around the notion of 'leveraging' patient interests and involvement in the research process for better conditions, experiences, and outcomes for patients in that process.

Our next contribution comes from Finland, in which Tuula Vaskilampi details the landscape of patient organizations in that country. Knowledge about patient organisations in Finland is still fairly limited, but Tuula highlights the insights – and further questions – which have emerged from the research thus far. Continuing on the theme of patient advocacy and involvement in healthcare, we then introduce a piece by Dr Francisco Suárez Sánchez and Dr Alvaro Quintero Posada, who report on efforts to institute a National Cancer Network in Colombia. We conclude with a contribution from Stuart Blume, who follows up on an article we published last year in the first issue of the Newsletter, describing an innovative project to mitigate leprosy stigma worldwide.

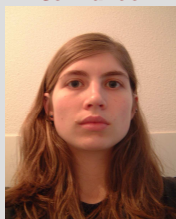
As always, we are excited to hear ideas and thoughts about work our readers are doing at the intersection of research, advocacy and health. We invite all readers to consider utilizing the Newsletter as a forum to share

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thinking (or events or opportunities or calls for collaboration, etc.), and to generally let the rest of us know what you are doing or envision doing in the future. Drop a line to Stuart Blume (S.S.Blume@uva.nl) or to either of the editors:

Dale Rose (Dale.Rose@fritzinstitute.org) or Zoe Goldstein (zoegoldstein@hotmail.com).

We hope you enjoy issue five!

Dale and Zoe

UPDATE ON THE BELLAGIO CONFERENCE PROPOSAL: PREVENTION AND PUBLIC HEALTH

Stuart Blume

I am happy to be able to say that work on an application to the Rockefeller Foundation for a return visit to Bellagio is moving ahead. Four substantive sessions are planned, and we are reckoning on three or four papers on each topic. The topics are outlined below, and you can also see who is taking responsibility for each of them. If you are interested in presenting a paper, please write to one of the session organizers, with a copy to Zoe Goldstein (zoegoldstein@hotmail.com). The date of the conference (assuming our application is accepted!) is not yet fixed but is likely to be somewhere between late 2008 and early 2009. In putting the programme together we will do our best to ensure that a wide range of perspectives is represented: a diversity that should reflect the interdisciplinary and international character of Innovia. Below are outlined the four main themes.

The social organization of preventive health

There has been a shift, in the field of public health, from a 'classical' approach in which states assumed (or were expected to assume) responsibility for the health of their citizens, to an approach that stresses personal responsibility. In this new approach individuals are assumed, and expected, to 'act responsibly' in their health-related behaviour. Some

commentators, in some places, argue that responsible behaviour (eating properly, exercising, not smoking, etc.) should be rewarded, deviance punished (for example by higher health insurance premiums). But what are the social, economic, and cultural factors that enable (or dis-enable) 'acting responsibly' in this sense? What role can and do community organizations or patient associations play in propagating ways of 'healthy living', de-stigmatization, and social inclusion? How are social inclusion and exclusion related to 'acting responsibly'?

** Organizers: Linda Hogle (University of Wisconsin, USA) and Stuart Blume (Amsterdam, the Netherlands). Contact Linda (lfhogle@wisc.edu).

The ethics of prevention

What are the moral grounds for interfering with peoples' decisions about their and their children's health? How justified are the demands of some parents that paediatric vaccinations should be subject to informed consent, and that they should be freely able to choose regarding what they take to be in their child's interest? When (and how) are limits on individual choice justified? By the risk of an epidemic? By the prospect of a future Dystopia? To what extent, and under what conditions, does appeal to the common good have moral force in a healthcare system governed increasingly by the laws of the market? There is a place for a deeper understanding of the 'moral' and ethical issues around prevention, including the justifications (if any) of different

forms of coercion.

** Organizers: Emilio Sanz (University of La Laguna, Tenerife) and Tuula Vaskilampi (University of Kuopio, Finland). Contact Tuula (tuula.vaskilampi@uku.fi).

Prevention of/for what?

Clearly prevention includes, but goes beyond, infectious disease control. What shapes the 'prevention agenda'? How and why is it moving beyond its traditional focus on infectious disease control? (And how is that traditional agenda influenced by fears of global pandemics?) For example, is obesity now becoming a topic for preventive action? If so why, and how are roles and responsibilities (e.g. of states and individuals) being conceived and assigned? Given the social and cultural differences in how body weight is perceived, how far can any preventive health-motivated campaign in this area justifiably go?

** Organizers: Kyra Landzelius (University of Gothenburg, Sweden) and Deanna Trakas (University of the Aegean, Greece). Contact either Kyra (kyra_landzelius@yahoo.com) or Deanna (d.trakas@sa.aegean.gr).

The tools of prevention: genetic screening

The armamentarium of preventive health has long included vaccines and vaccination, and various kinds of coercions (including, most importantly, restrictions on movement such as quarantine, etc.). The focus here will be specifically on prenatal genetic testing, a much more recent tool of preventive health. What is driving the extension of genetic testing? What kinds of coercions are involved, and how does the meaning of testing differ from place to place? Under what circumstances does it make sense to talk of 'eugenics by the back door'?

** Organizers: Alastair Kent (Genetic Interest Group, UK), and Rayna Rapp (New York University, USA). Contact either Alastair (alastair@gig.org.uk) or Rayna (rayna.rapp@nyu.edu).

If you would like to present something that doesn't quite fit under any of these topics, but does relate to the overall theme of prevention, I invite you to please write to me (s.s.blume@uva.nl). We might be able to fit it in somehow!

GET TO KNOW... **CHAN Chee Khoon**

I was born and raised in Penang, Malaysia, completed high school in Kuala Lumpur, and then proceeded to college in the United States. My undergraduate and graduate studies in biological sciences were followed by a doctorate in epidemiology, which I like to think of as the social ecology of health and disease.

One could say that two strands of endeavour have fed into this (social ecological) perspective – an amalgam of Thomas McKeown and Michael Marmot – but to my mind, this still

doesn't quite capture my view of it as an interpenetrating unity of the biological and the social (an example here would be putative neuro-endocrine processes linking inequality and social status with stress and diverse chronic morbidities). Another way to understand the social ecological approach is through the work of Richard Levins, who founded a working group on emerging and re-emerging infectious diseases at the Harvard School of Public Health in the 1990s, and gave an award lecture for the Edinburgh Medal of Science in 1996 (*When Science Fails Us*) [1]. This lecture is arguably one of the founding statements of the social ecology of health and disease in its modern incarnation.

In my previous engagements with policy issues in emerging biomedical technologies (and more recently, access to essential medicines), I have tried to locate these concerns within this broader perspective. While this perspective allows for a sense of proportion and relative priority regarding the determinants of population health (even as one acknowledges the need to act upon manageable problems while pushing the boundaries of the feasible), it nonetheless lacks the individual empathy of a caregiver's perspective, not to mention the subjectivity of the patient or patient surrogate's perspective. In any case, the HIV/AIDS pandemic has lately alerted us to the porous boundary between treatment and prevention, and has taught us that a patient-centred approach can be an important, integral part of a population health approach to disease control.

In 2001, Gilles de Wildt and I met in Geneva as civil society representatives making submissions to a WHO consultation on Genomics and Health [2]. Over the next few years, we started discussing the potential leverage that volunteers in clinical trials, laboratory-based studies, and other research settings might have in influencing the direction and priorities of research as well as the disposition of benefits arising from such research (specifically more equitable access to healthcare emerging from such endeavours). It was about that time that I was fortunate to connect with Stuart Blume who very kindly invited me to participate in Innovia's 2002 inaugural conference at Bellagio.

When the Indonesian government decided in early 2007 to withhold avian flu virus samples from WHO's collaborating centres (as a bargaining ploy for better terms for developing countries), it immediately struck us that they were doing at a national level what we had been pondering as individual or community interventions. The upshot was a working paper on donor leverage that was posted at the UN Dept Economic & Social

Affairs website (UN DESA): http://www.un.org/esa/desa/papers/2007/wp41_2007.pdf. This has since been published [3]. (We subsequently learned that PXE International in the US, an advocacy group for patients with *pseudoxanthoma elasticum*, had embarked upon an initiative along quite similar lines [4]).

The concluding part of our paper lays out a research plan in outline for a potential multi-country collaboration. In parallel with working on a research proposal and study protocol, we are also considering drafting a provisional Volunteers' Charter, which could reciprocally inform the research effort as the venture evolves. The charter could therefore be one tangible product of the research effort, which research volunteers, patient networks, and patient advocates could consider, customize and modify, endorse, adopt, or use as a basis for interacting with research entities and funders, commercial developers of downstream products, policymakers, legislators, etc.

Gilles and I would be delighted to collaborate with Innovia members who might have an interest in a venture of this nature.

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References:

- [1] Levins, R. (1996) When Science Fails Us. *Award Lecture: Edinburgh Medal of Science, 1996*. Text available at: <http://pubs.socialistreviewindex.org.uk/isj72/levins.htm>
- [2] Chan, C.K. (2004) Genomics, Health, and Society: A View from the South. In *Genomics in Asia: A Clash of Bioethical Interests* (ed. Margaret Sleeboom). London: Kegan Paul.
- [3] Chan, C.K. & G. de Wildt (2008) Donor Leverage: Towards More Equitable Access to Essential Medicines? *Development in Practice* 18(1):100-109.
- [4] Rimmer, M. (2006) Miami Heat: Patent Law, Informed Consent, and Benefit-Sharing. *Journal of International Biotechnology Law* 3:177-192.

PATIENT ORGANISATIONS IN FINLAND FROM A CULTURAL AND SOCIAL VIEWPOINT

Tuula Vaskilampi

Patient organisations in the context of Finnish society

Patient organisations in Finland were established and now exist within a certain cultural and historical context in which the official healthcare system is particularly important. In the development of patients' movements, the rights and obligations of citizenship are being defined as well as the role of community and the whole society at large (i.e. at State level). It can be argued that the shared interests, sufferings, and visions for a better future create collective movements in the case of illness, and the felt experiences of the people must be crucial in this organising process. In fact, patients' organisations express an activism of citizens and the current stage of society.

The Finnish healthcare system has been historically built up in the Nordic Countries' tradition, according to which local communities (municipalities) carry the responsibility of caring for its own old and sick people. The Finnish Constitution also declares that the State has responsibility for the health of its citizens. The present healthcare system is still provided by local municipalities, financially compensated by Central Government, and the rights for health services are based on citizenship of the municipality. There exists both a private and public healthcare system in Finland, and health costs are largely covered by public Health Insurance.

The Industrialization process and the Welfare State came quite late and rapidly in the 1960s and '70s in Finland. It has been typical for

Finnish culture to appreciate work, independence, and individualism; a certain kind of Protestant Puritanism. For instance, depression and burn-out phenomena in the working age population are very common. It can also be argued that one of the visible characteristics of the Finns is obedience towards officials, teachers, university degrees, scientific research, and printed words! Though while Finnish culture has been labelled as homogenous, it is now changing.

Patient organisations: structure and activities

It is striking how little systematic, survey-type research on patient organisations (POs) exists, even though their visibility and influence seems to be increasing in western post-industrial societies. The latest large-scale survey on Finnish POs, specifically focusing on their structures and functions as well as physicians' attitudes

towards them, was carried out by Hanna K. Toiviainen [1] and her study group [2]. The remainder of this section is based on these studies.

National POs have been established in Finland since the 19th Century, and have promulgated increasingly since the 1970s and exponentially since the 1990s. The number of identified health-related POs in 2002 was 130; the population of Finland is 5.2 million. The oldest organisation is the Finnish Association for Mental Health, established in 1897. Following this, organisations arose for seeing- and hearing-impaired individuals, and especially after the Second World War several POs were established for a variety of disability groups. In more recent years, POs have formed to address rare and previously unknown diseases.

POs are, of course, focused on different patient groups and diseases. They have been



founded by philanthropists, physicians, patients, parents, and the pharmaceutical industry. Members of these organizations could be patients, patients' relatives, healthcare professionals, and organisations themselves. The size of Finnish POs varies greatly, ranging from 20 to 145,000 members. The largest is the Cancer Society of Finland (with 145,000 members), the second largest the Finnish Heart Association (85,000 members), followed by the Finnish Rheumatism Association (54,000 members).

POs also vary according to their organisational structure and decision making processes. A multi-level, hierarchical structure is typical for Finnish POs. In other words, there are national, regional, and local levels. In terms of governance, interest groups and funding providers are often represented in decision-making bodies. However, POs largely receive their funding from public sources, including Finland's Slot Machine Association (RAY), among others. In addition, membership fees and private donations are important in some organisations. Voluntary work plays a very important role within these organisations, although the older and larger ones also have salaried staff.

Activities include mutual support and service provision as well as information dissemination and lobbying. It is typical for activities to range from a focus mainly on sick individuals to broader work related to health and social change (including health education and general counselling). PO web pages often carry implicit advertising for health technologies, and moreover, in some cases it is mentioned on these sites that counselling and other activities – including training courses for healthcare personnel – are sponsored by a drug firm. Finally, at a societal level, POs have been the 'watch dogs' of official services and have tried to influence health policies such as reimbursements for drugs and treatments for their members and constituents.

The role and function of patient organisations in society

POs carry out both expressive and instrumental activities. They help to address the worries, problems, and practical needs of individuals during times of health and illness with methods of collective movements. The crucial question is: who are they actually representing? Are they representing the interests of patients, healthcare personnel, or the pharmaceutical industry? And beyond that, the question is one of overlap: are these interests at all congruent?

In spite of the differences between them, Finnish POs have in common the fact that they are lay movements that are tightly interwoven with healthcare professionals and the structure and activities of the healthcare system. Few of the POs can be regarded as 'self-help' groups (in Finnish society these are quite marginal). Rather, POs represent 'the establishment' within their healing cultures and activities and, as noted already, some of them are quite dependent on funding by the drug industry.

On a final note, there are some social health movements based around alternative medicine, but they have not established visible POs. It can be argued that there are some signs of a transformation of the traditional passive patient role into an active, subject, client role. However, according to opinion surveys these changes – defined as consumerism – have not been welcomed by the Professional Medical Associations [3], [4].

References:

- [1] Toiviainen, H. (2007) *Konsumerismi, potilaiden ja kuluttajien aktiivinen toiminta sekä erityisesti lääkäreiden kokemukset ja näkemykset potilaista kuluttajina. [Consumerism, patients' and consumers' active behaviour and, in particular, physicians' experiences and views of patients as consumers.] STAKES, Research Reports 160. Helsinki.*
- [2] H. Toiviainen, L. Vuorenkoski, & E. Hemminki (2008). Patient organisations in Finland: Increasing numbers and great variations. In Press.
- [3] Toiviainen, H., L. Vuorenkoski, & E. Hemminki (2004) Finnish Physicians Show Little Support for Consumer Advertising of Prescription Drugs. *The New Zealand Medical Journal* 117(1195): 1-3.
- [4] Toiviainen, H., L. Vuorenkoski, & E. Hemminki (2005) Physicians' Opinions on Patients' Requests for Specific Treatments and Examinations. *Health Expectations* 8: 43-53.

THE CANCER NETWORK INITIATIVE IN COLOMBIA

Francisco Suárez Sánchez, MD
& Alvaro Quintero Posada, MD

The Instituto Nacional de Cancerología (National Cancer Institute of Colombia), or INC, has two main areas of work. It contains a public hospital specialising in cancer treatment, which is open to patients who are insured both through public and private health insurance schemes, as well as to the poor and uninsured. It also contains a Public Health and Research team, which gives advice on cancer-related issues to the Health Ministry, as well as to other governmental and private organizations.

The legislation establishing INC required it to organise and coordinate a National Cancer Network, intended to facilitate the equitable provision of treatment to cancer patients, and the efficient use of available resources. Thus, the 'Group for Assessment and Follow-up of Oncology Services' was created and assigned this task as its main responsibility.

In order to establish the network, it was felt necessary to attempt to characterise the cancer care available throughout the country. Experts gathered to discuss and agree upon a definition of the national cancer network, to establish different interests in the functioning of such a network, and to agree upon how it could be established. Involving patient movements in these discussions was problematic due to the fragmentation of cancer patient associations in Colombia. Instead of there being a single association, speaking with one voice, there are numerous organisations each claiming to represent cancer patients, but with very different objectives. For example, whilst some demand advances in diagnostic and therapeutic technologies, others are more concerned with humane care and respect for the individual.

By definition, the National Cancer Network is conceived as a resource that may enhance and improve information flow and bring benefits to those involved in it. There is a

valid and genuine interest among all cancer-oriented groups, from hospitals to foundations, to work in and for the network. As discussions proceeded, these interests became clearer. The network would help bring about greater equity in access to treatment, helping to compensate in some way for economic and regional disparities, and it would have to help ensure speedier and more accurate diagnosis.

In parallel with these discussions, a national survey was sent to cancer facility CEOs and directors, private oncologists, and executives of insurance companies. It asked for information about demand, performance, costs, and ways to assure quality, integrity, and equity in treatment. This study was intended to characterise the cancer care market in Colombia.

Provisional, not yet published results of the study show that cancer care in Colombia is predominantly provided by private institutions, at 72%, compared to 28% by public sector hospitals. The study points to great disparities between the two in terms of development and performance, and in terms of technology acquisition and use. It points to equally large disparities from one region to another, and from one city to another in the same region, as well as within the same city perimeter. Further analysis of the survey is currently ongoing. Despite all the regulations, central control over cancer services is weak, making a coordinated



approach to tackling inequities difficult.

Colombia is not only a large country, it is culturally and economically a very diverse one. Promoting equity in cancer care has faced many challenges. As regional differences became clear, discussion among various regional groups was initiated. The objective was to establish common interests and common ideas on the viability and usefulness of a cancer network, as well as the obstacles and opposition to its implementation. As a result, a technology and knowledge management network was proposed, and this will be tested in two areas of the country.

Trying to establish this Cancer Network is a new experience for the INC and for the Colombian Ministry of Health. We would like very much to hear about comparable initiatives in other parts of the world. Of course, we know that other people's experiences cannot simply be appropriated; they are the product of the

environments in which they were developed. We also know that there is no standard pathway towards establishing networks or having them work effectively. But we think we can still learn from other people's experiences in network-building. Social scientists have established that networks start from common interests, and that they become stronger as bonds tighten and as trust and confidence grow among the actors involved. Networks imposed from above may run the risk of failing to achieve their central goals. We want our initiative to make a significant contribution to the quality of cancer care in Colombia, and to more equitable access to these services.

Grupo Evaluación y Seguimiento de Servicios Oncológicos (INC), Bogotá, Colombia.

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THE STIGMA OF LEPROSY (2)

Stuart Blume

In the first issue of this Newsletter (March 2007) I wrote about a collaboration Innovia was planning with IDEA (the International Association for Integration, Dignity and Economic Advancement). This is an international advocacy organisation for people whose lives have been challenged by leprosy (also known as Hansen's disease). You can visit their website at www.idealeprosydignity.org.

In March 2003 IDEA launched its Global Campaign to eliminate the stigma still associated with leprosy in much of the world. Nine major steps were identified:

1. Acknowledge that the stigma can be eliminated;
2. Promote a positive image and emphasize the legacy of creativity and inspiration;
3. Build bridges towards universal human rights and peace through the IDEA Centre for the Voices of Humanity;
4. Respect and promote the dignity of the older generation of individuals affected by leprosy by using their life experiences to effect social change;
5. Ensure that individuals affected by leprosy are accorded their rightful place in their own history;

6. Continue to expand IDEA's international network of support;
7. Promote opportunities for empowerment, education, and economic independence;
8. Encourage and support the restoration of family ties;
9. Recognize and promote an understanding of the deep emotional issues that continue to accompany a diagnosis of leprosy, and encourage the development of programmes and activities to assist individuals with the resolution of these issues so that they may lead lives without added, unwarranted stress resulting from the burden of stigma and secrecy.

How can research contribute to the achievement of these goals? What can be learned from experiences in combating the stigma of leprosy in different parts of the world? These were the questions Innovia hoped to address. Our idea was to begin by producing an annotated bibliography of studies of leprosy-related stigma and initiatives taken to combat it in different parts of the world. Reviewing this literature, we would then consider the possible value of further comparative research. Unfortunately, this plan foundered at the time and we were unable to proceed.

Now I am happy to say that we are in a position to make a start. Lesley Jo Meek, a graduate student at Emory University (Atlanta, USA), is willing to take on the task. Jo is working both for her Master's in Public Health

and for a PhD in Anthropology. Before moving to Emory, she spent a year in Varanasi, India, doing ethnographic work at a leprosy colony, where she focused on patients' lived experience of stigma. If you would like to join the e-mail discussion group and contribute to this work you can contact Jo (lweaver@emory.edu).

Moreover, Wim van Brakel, who is a public health specialist at the Royal Tropical Institute (KIT) here in the Netherlands, recently sent me an interesting e-mail. He wrote:

We are about to finish compiling a mailing list of people who attended a 'Social Science and Leprosy Stigma meeting' which I convened at the recent International Leprosy Congress in Hyderabad, India. We have merged in a previous list from a similar workshop I organised in Delhi a number of years ago. I will circulate the list to this group when it is finished and hope that it will be useful as a forum for Jo and others, since the people on the list represent a very wide range of experience and expertise with regard to leprosy-related stigma and its consequences.

Wim also drew our attention to the e-Forum of ICRAAS (International Consortium for Research and Action Against health-related Stigma):

www.dgroups.org/groups/stigmaconsortium.

I think there is now good reason for hoping that this work will develop into an exciting Innovia initiative, and a demonstration of how useful a resource research can be for the patient movement and for health-related advocacy groups.